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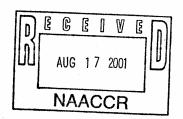
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August 15, 2001



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Holly L. Howe, PhD. **Executive Director** North American Association of Central Cancer Registries 2121 W. White Oaks Dr., Suite C Springfield, Illinois 62708

> Re: The Federal Privacy Rule's Application to Central Cancer Registries

Dear Dr. Howe:

EDWARD J. CUNNINGHAM ROBERT A. STUART, JR. J. PATRICK JOYCE, JR. ERIC L. GRENZEBACH JEFFERY M. WILDAY WILLIAM F. TRAPP BALII BOWN

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At your request, we have reviewed the letter dated July 13, 2001, which you received from Professor James Hodge of the Georgetown University Law Center. As discussed by Professor Hodge, federal regulations, entitled Standards for Privacy of Individually Identifiable Health Information (the "Privacy Rule"), restrict the use and disclosure of health information by health care providers, health plans, and health care clearinghouses. After reviewing the relevant regulations, Professor Hodge concluded that the Privacy Rule does not restrict the disclosure of patient information by a health care provider to a central cancer registry so long as the central cancer registry is a "public health authority." We agree with that conclusion.

On July 6, 2001, the U.S. Department of Health and Human Services ("DHHS") issued its Guidance on the Privacy Rule and on the issue addressed by Professor Hodge.² DHHS concluded that disclosures to public health authorities are permitted under the Privacy Rule, and among various Questions and Answers, stated:

¹ 45 C.F.R. § 164.500 et. seq.

² Guidance on Standards for Privacy of Individually Identifiable Health Information, issued by the U.S. Department of Health and Human Services, at pg. 54 (July 6, 2001).

- Q: Must a health care provider or other covered entity obtain permission from a patient prior to notifying public health authorities of the occurrence of a reportable disease?
- A: No. All states have laws that require providers to report cases of specific diseases to public health officials. The Privacy Rule allows disclosures that are required by law. Furthermore, disclosures to public health authorities that are authorized by law to collect or receive information for public health purposes are also permissible under the Privacy Rule. In order to do their job of protecting the health of the public, it is frequently necessary for public health officials to obtain information about the persons affected by a disease. In some cases they may need to contact those affected in order to determine the cause of the disease to allow for actions to prevent further illness.

The Privacy Rule continues to allow for the existing practice of sharing [protected health information] with public health authorities that are authorized by law to collect or receive such information to aid them in their mission of protecting the health of the public. Examples of such activities include those directed at the reporting of disease or injury, reporting deaths and births, investigating the occurrence and cause of injury and disease, and monitoring adverse outcomes related to food, drugs, biological products and dietary supplements. (emphasis added).

As explained by DHHS in its Guidance, the Privacy Rule allows disclosure of information to public health authorities. With respect to the disclosure of information to central cancer registries, and as noted by Professor Hodge, whether the Privacy Rule restricts the disclosure of information depends on whether each central cancer registry falls within the definition of a "public health authority." A public health authority is defined as:

an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency...that is responsible for public health matters as part of the official mandate.³ (emphasis added).

³ 45 C.F.R. §164.501

Since state cancer registries come within this definition, the Privacy Rule does not restrict disclosure of patient information to them. For the exemption to apply to a non-governmental registry, however, the registry must operate pursuant to a contract with a public agency or under a grant of authority from a public agency.

Should you have any further questions regarding this issue, please advise.

Very truly yours,

Jeffery M. Wilda

JMW:ddh